Parents' adjustment to cancer in children

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Chapter 7

General discussion
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INTRODUCTION

This thesis uses a stress-coping model (based on Lazarus 1984)[1], for understanding the effects of pediatric cancer on parents general mental health. We examined psychological distress caused by dealing with cancer and the ability of parents to adjust to the experience after five years by looking at the way parents cope with and adjust to the experience across this time period. The end results of a five year prospective longitudinal study on parental adjustment to pediatric cancer based on the evidence across the five years are the subjects of this dissertation. Results from the first year after diagnosis, using three measurement points, have been previously published[2-6]. However, the data obtained from earlier measurement points are analyzed for this thesis in conjunction with the last measurement point at five years after diagnosis. This provides the opportunity to gain insight into the psychological adaptation process of parents over a longer period of time and to gain insight into short- and long-term risk factors for psychological dysfunction.

Despite the progress in understanding the effects of pediatric cancer within the context of parents as caregivers, the way it affects parents personal lives throughout the years remains relatively undisclosed. The aim of this study therefore is to gain insight into the adjustment of parents over a longer period of time.

The discussion focuses on the five year outcome, parental adjustment, in relation to demographic and illness-related variables; (change in) distress, anxiety and psychological complaints across time; coping strategies; (personal and professional) social support and satisfaction with this support; marital satisfaction and communication between spouses; risk factors for adjustment and further research possibilities; and parents' willingness to participate in interventions. The discussion closes with consideration of practical implications for psychological and social care.

General characteristics of the studies

The studies included in this dissertation have a prospective, longitudinal design and aim to examine parents' psychological functioning at five years after diagnosis as an indication of their psychological adjustment over time. Parents filled in questionnaires at four time points, namely at diagnosis (T1), at six (T2) and twelve months (T3) after diagnosis, and at five years (T4) after diagnosis. The focus of the present thesis is on parents' functioning at five years and adaptation over time and on factors predictive of their functioning. The measures we used were self-report questionnaires on psychological distress, symptomatology, and anxiety (GHQ, SCL-90, STAI-S); coping (UCL); social support (SSL-I, SSL-D); Marital Satisfaction (MMQ) and Communication within the marriage (CSI). Parents also provided information on socio-demographic and illness-related variables.

The number of parents who responded remained fairly consistent over time with 74 percent of the respondents at diagnosis also responding at five years after diagnosis (115 parents). This response rate enabled us to receive a reasonable impression of how the parents coped over the years. Non-response at the two measurements of 6 and 12 months after diagnosis was either caused by deliberate exemption at those times because of the death of the child (36 parents), death of the parent (3 parents) or they had relocated (6 parents). At five years after diagnosis, all eligible parents (155 parents), including those exempted at T2 and T3, were asked to participate. Ninety-six parents responded at all 4 measurement points.

In addition, parents were also invited to participate in a part of the study that was aimed at examining the effect of an intervention on their psychological functioning. Consequently, randomization took place at T1, thus making this study also a randomized clinical trial. However, not all parents participated in this part of the study. Some parents restricted their participation to completion of questionnaires on their psychological functioning at the different measurement points.

OUTCOME

Parental psychological functioning at five years and adjustment over time

Our findings correspond with those found in the literature on parental and family adjustment to cancer in that most parents do appear to adjust well to pediatric cancer over time[7-10]. On group level, parents reported a significant decrease in mean levels of psychological distress, psychological complaints and state anxiety on all of our measures. On individual level , 73% showed no clinically elevated levels of distress at five years after diagnosis of cancer in their children. However, a significant percentage of parents, 27% as compared to 15% found in the norm population[11], do not seem to adjust well and may suffer from chronic (dis)stress. This last finding could be in line with recent studies that have identified post-traumatic stress symptoms and in some cases post-traumatic stress disorder in parents of pediatric cancer patients especially in bereaved parents and mothers up to five years after end of treatment or death of their child[12-14.]

In addition, when we look closer at changes in levels of distress in individuals, the above mentioned decline in distress in our study was not always linear. Though not mentioned previously, we do see different patterns in the responses of individuals on the measure for distress (GHQ) across the four measurement points. Some individual parents who reported a clinically elevated level of distress at diagnosis (GHQ score >3) remained clinically distressed at all time points (15%, 14 of 96 parents). Other individuals who reported a distress levels below the cut-off point maintained this across the four measurement points (8 %, n=8). In a larger group of individual parents, we see a decline

in scores from high at T1 and T2 to low at T3 and T4 (23%, n=18) or high at T1,T2 and T3 and then low at T4 (17%, n=16). These last two patterns correspond roughly to scores that are clinically above the cutoff during treatment followed by scores below the cutoff after treatment. The other parents have scores that show a wavelike pattern of responses with scores that sometimes meet the clinical cutoff alternating with scores that do not. In this light we can mention another model that has been put forward coming from research on the stress response system[15,16]. In this model, changes in distress over time can be explained in terms of a non-linear (wavelike) pattern of changes between experiencing intrusive, unwanted negative thoughts and emotions alternating with attempts to avoid these thoughts and emotions.

Socio-demographic and illness related variables

Based on the literature, gender and age of the parents or child, education, marital or socioeconomic status, were considered as potential predictors of parents' later psychological distress[5,7,8,17-22]. In our study, more parents of deceased children, older children, and from lower educational levels did not respond at the last measurement point. Although most of the non-response was due to being lost to follow-up, some non-responders also did so because of the emotional strain it could cause. This may have had an effect on generalizability.

In most studies, mothers are found to express more distress than fathers[2,7,22-26]. We found gender to be relevant to state anxiety but not to general distress or psychological symptoms. Mothers report a significantly higher level of state anxiety than fathers at all measurement points. A second finding related to gender was that the amount of initial distress experienced by fathers significantly affected their distress at five years after diagnosis, while this was not found for mothers. Therefore, when looking for predictors of distress, anxiety in mothers and high initial distress levels in fathers could possibly be seen as risk factors for their later distress. The difference between mothers and fathers is notable, and to speculate on the reasons for this, one possibility that comes to mind can be found in the traditional social role differences between men and women[2,27,28]. Also, a difference in ways of coping between men and women could play a role. More studies including both parents are needed to further elucidate the possible different trajectories mothers and fathers experience during the process of dealing with pediatric cancer.

The illness-related variable examined in this study was health status of the children at five years (survived, deceased or relapsed). Health status of the children provides a partial explanation for higher levels of distress at five years. When children have suffered a relapse of their cancer, the levels of general distress and state anxiety reported by parents five years after diagnosis are significantly higher as shown by parametric and non-parametric tests of significance. However, the number of respondents in this category is very small (n=8). So this finding must be viewed with caution. We also find a significantly

higher level of state anxiety in parents of deceased children in comparison to parents of children who survived their cancer. These findings are congruent with other studies on parents of deceased children[29-33]. In the light of the expectations from the literature, it is at the very least notable that of the socio-demographic and child health related variables we measured only two were found to affect parents' distress at five years and the effects of these on parents' distress at five years were small.

Coping

Our findings illustrate that coping seems to be a situation-specific process and that coping predictors vary as a function of parents' gender. Over the five years following diagnosis, parents use of social support seeking decreased and expression of emotions increased linearly, and use of active problem focusing, avoidance, passive reaction pattern and comforting cognitions decreased after diagnosis and then showed an increase. Use of palliative reaction did not change over time. So it seems that after diagnosis, during treatment, the use of the different coping styles changes as change in situation demands. After treatment has ended, five years later, the use of the different coping styles more closely resembles that of coping in general (compared with a norm population). It is notable that a difference in use of coping was found between fathers and mothers with regard to change in coping. We attempted to discover whether initial distress and coping had noteworthy effects on adjustment after five years. We only found significant associations of initial distress with distress five years later for fathers and not for mothers, as pointed out two paragraphs above. This was unexpected. Other differences between fathers and mothers were found in changes in coping predictive of later distress. Mothers showed a unique association of change in social support seeking with increased distress five years later, and fathers a unique association of change in use of active problem solving and passive reaction pattern. However, the amount of explained variance for these associations is very small. This leaves room for speculation begging the question as to whether our measures of coping adequately reflect the manner in which coping (styles) affects parents' adjustment to pediatric cancer. Parents may use coping styles not captured in the UCL (Utrecht Coping List), such as those generating hope and optimism[33-39]. It is also possible that other factors, such as personality characteristics of parents and children affect adjustment more than coping styles do[5]. Another possibility is that, other life events, not measured here, could influence parents' adjustment to cancer in their children.

Social support

Taking a closer look at social support, as measured by the Social Support List, shows the quantity of support received according to parents to be largest at diagnosis and to decline significantly as time passes for both mothers and fathers. This is also in accordance

with the social support subscale of the UCL that assesses social support seeking. So parents seem to receive and seek less support as time passes. However, mothers continue to experience more supportive interactions than fathers across the five years. And, there is a significant difference in the effects of support on the psychological functioning of fathers and mothers both concurrently and prospectively at 5 years after diagnosis. Concurrent dissatisfaction with support and negative interactions experienced by fathers significantly affect their levels of psychological distress at 5 years after diagnosis. Fathers who are dissatisfied with the support received also report higher levels of distress. Also, to a lesser extent, a larger number of negative interactions are associated with fathers' greater distress at 5 years. These effects are not found for mothers. The difference between mothers and fathers in social support as we found it could possibly be explained by differences in types of support networks. Women have been reported to rely more on family and friends for support while men rely more on contact with colleagues[28,40]. It may be that family and friends offer a more personal type of support that is more in harmony with the support needs of mothers dealing with pediatric cancer. Fathers may receive a level and/or type of support from colleagues that do not necessarily meet their needs (as one father in our study remarked).

Most studies on social support and cancer in children do not include data on the satisfaction with support. A recent review of the literature suggests that examining differences between desired support and received support could provide us with tools for modifying support in a positive direction[14]. In accordance with this notion, we found that dissatisfaction with received support, especially in fathers of pediatric cancer patients, was a significant predictor of greater distress over time. Interventions aimed at alleviating dissatisfaction with support by tailoring the support more to expressed needs could possibly affect distress in a positive direction[14,41]. Recent studies have found positive associations between benefit finding, a positively-oriented coping strategy that involves looking for the positives or benefits in adversity, and social support in cancer populations[42,43].

Marital (dis)satisfaction and communication

Although expected, pediatric cancer does not seem to have a negative impact on parents' marriage five years post diagnosis. At any rate, 95% of the parents in this study remain married at the five year measurement point. Even though this is the case, marital dissatisfaction of mothers does increase from one to five years over time. The effect size of this increase is small. Higher levels of avoidant, incongruent and destructive communication between partners at diagnosis are significantly associated with marital dissatisfaction five years later for both mothers and fathers. Mothers report less intimacy in communication than fathers do. Also, for mothers, lower intimacy scores at diagnosis are significantly associated with higher marital dissatisfaction scores at five years after

diagnosis. Remarkably, mothers' marital dissatisfaction at our first measurement point has a large impact on her dissatisfaction reported at five years later while for fathers this effect is quite small. Thus, the quality of communication within the marriage, as we measured it, does seem to have an impact on the amount of marital dissatisfaction.

However, it is notable that we found no significant impact of marital (dis)satisfaction at diagnosis on parents' distress at five years after diagnosis. The impact of communication at diagnosis on distress five years later also was limited to a univariate effect of avoidant communication for mothers and a univariate effect of destructive communication for fathers .

Although few studies focus on parents' marital quality, some studies on parents of pediatric cancer patients have found that the majority of parents did not report a negative effect of the cancer experience on their marital relations. Some parents even have reported their marriage to have been strengthened by the experience of caring for their child with cancer while a subgroup reported marital difficulties[12]. Our results seem to be in congruence with this finding.

Risk factors for adjustment and future research questions

Based on our findings we would suggest that, over time, though most parents adjust well to cancer in their children, a significant number of parents are clinically distressed at five years after diagnosis. We looked at socio-demographic and child health related variables; coping; social support; quality of the marriage relation and communication between marital partners. None of these variables could sufficiently explain the psychological functioning of parents at five years after diagnosis. The only variables we looked at that had any, even small effect, on parental adjustment were: gender and health status of the children (social-demographic); a very small effect of different coping styles, and a bit more for social support; and a small effect of marital satisfaction including the way parents communicate with one another. Thus, seeing the small percentage of variance explained by these factors, we must look to other variables that may also affect parents' adjustment to their child's cancer.

Recently, attention has been drawn to the possibility that adversity such as found in pediatric cancer can draw out positive adaptive qualities such as hope and development of resilience[34,37,43,44]. Resilience has been defined as showing forward movement, developing new purpose or meaning, and absence of emotional distress[33]. It certainly may be the case that some parents in the present study developed positive adaptive qualities such as learning to maintain hope and resilience while dealing with their child's cancer. Remaining hopeful and resilient could have positively affected their level of distress. It may well be that low levels of distress, good use of coping and social support as well as being satisfied with one's marriage and communication with one's partner are all indicators for positive adaptation or of resilience. Unfortunately, this study did not

include explicit measures of resilience and hope, this could be a fruitful future direction for further research.

Also, studies of resilience among parents of children with cancer have shown that persons with fewer resilience resources such as optimism and self-efficacy are more at risk for poor psychosocial adjustment[44]. This could also be the case for those in the present study who remained distressed after five years. Future research on risk factors may need to focus on factors such as resilience and hope. Another avenue of possible investigation is to look at personality characteristics of parents[5,45] and family structure[46]. Investigating these aspects of functioning could help to uncover important factors affecting long term adjustment[5].

Also needed is more understanding of the effects of bereavement on parents' adjustment. In our study only a small group of parents who had lost their child participated at the last measurement point. Data from bereaved parents who declined participation at 5 years could have given us a clearer view of their distress.

Although we have gained some knowledge on the factors that influence distress in parents, more prospective longitudinal research is needed to fully understand differences between mothers and fathers in distress across time[14]. Specifically, research could focus on differences in adjustment trajectories in relation to specific aspects of treatment and outcome variables[14,46].

PSYCHOSOCIAL INTERVENTIONS

Parents willingness to participate in a psychosocial intervention study

Attempting to identify factors that indicate whether parents are willing to randomize in a study to examine the effect of psychosocial interventions could be helpful in caring for families dealing with pediatric cancer. We looked at the differences between parents who were willing to randomize for psycho-educational intervention (aimed at alleviating distress and enhancing coping skills) at the beginning of the study (within 14 days after diagnosis) and those who declined randomization. No significant socio-demographic or illness related differences are found between the groups of parents willing to participate in a study examining the effect of an intervention and those who are not. However, parents who are willing to randomize for a study and participate in an intervention show as a group significantly higher levels of psychological distress at diagnosis than those who do not want to randomize for an intervention. Also, dissatisfaction with social support is a significant factor in the choice to randomize. No other significant differences between the groups are found in either quantity of social support or marital satisfaction

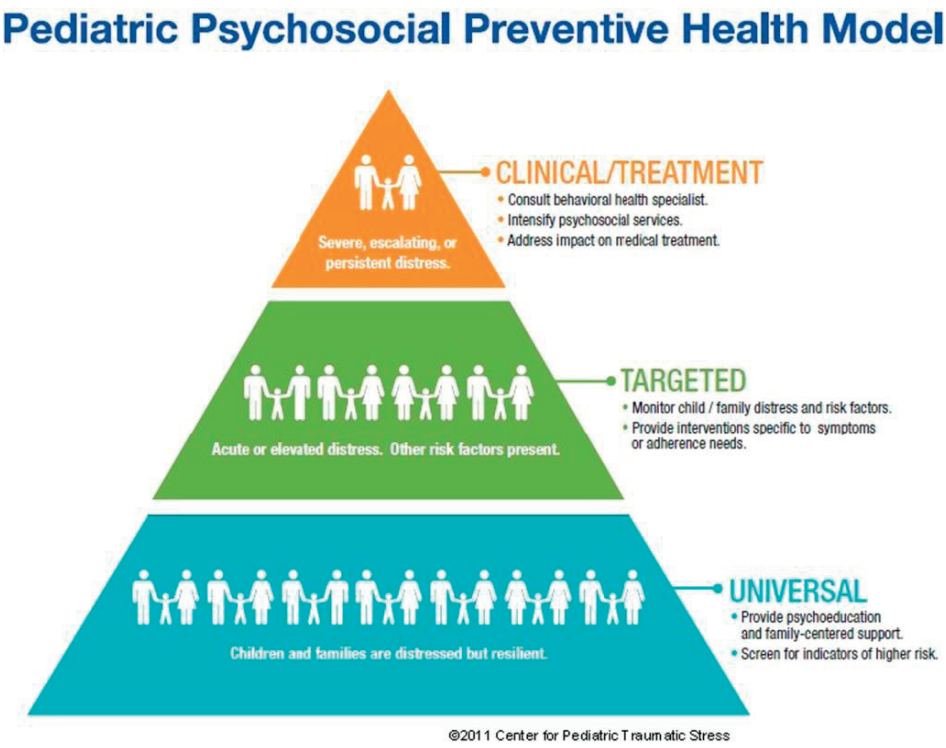
Thus, our secondary analysis of the psychosocial intervention data suggested that parents seem to be, for the most part, able to estimate their own needs for interven-

tions. It also showed that some of the participating parents may have had less need for an intervention. Therefore, it seems likely that it is more effective to offer interventions only to those parents who indicate they are (highly) distressed (at diagnosis and during treatment) and who express a need for professional help. This could be the case unless, from a prevention perspective, characteristics are found that indicate risk for developing problems later on.

Screening for distress and psychological interventions

For the clinical practice, regular screening by health care providers should be aimed at finding those individuals who are in need of and express the need for interventions aimed at decreasing distress, and promoting resilience and mental health. Screening for distress helps scientists and clinicians to better focus on patients and their families who may need professional psychological help. As our research has shown, at least a third of the parents of pediatric cancer patients are distressed up to five years after diagnosis and regular screening could help identify these persons at an earlier date and possibly prevent long term maladjustment. One of the important reasons for engaging in psychosocial screening is that it facilitates clinical care[47]. Screening for psychosocial problems can lead to better communication between health care providers and parents, when the focus of the communication is on dealing with mental and social aspects of treatment. However, the practice of broad screening for psychosocial needs in cancer patients has been questioned[48]. Researchers have based their arguments on the lack of consensus and well-defined definitions of screening and distress[49]. Basically, the argument has been made that there is a lack of evidence that the practice of distress screening actually results in benefits for patients. There is also evidence that when communication with patients improves through appropriate screening this also leads to more referrals for psychological care[50-52]. It may then seem better to offer referrals for psychosocial care to those who actually express a need. Therefore, it seems most beneficial to offer screening in combination with clinical care integrated within a comprehensive care model. One such model that has been used with some success in the USA in pediatric oncology is the Pediatric Psychosocial Preventive Health Model (PPPHM) developed by Kazak et al.

This model provides for different levels of intervention and includes screening for indicators of higher risk which will lead from a universal level of psychosocial health care to a targeted and clinical intervention levels. On the universal level psychosocial care can be provided by nursing staff. The levels of acute or elevated distress require more professional care such as provided by social workers and clinical psychologists. Severe distress requires interventions by clinical psychologists and psychiatrists. This is in tune with recent ideas about stepped en matched care.



The present day focus in general is on family based interventions whereas this dissertation only deals with parental adjustment. In the Netherlands, the Psychosocial Assessment Tool (PAT)[53-55], used in conjunction with above mentioned model, and the Pediatric Inventory for Parents (PIP)[56] are used for screening of risk in families of pediatric cancer patients. The PAT is currently being studied as a potentially valid instrument for use with families of Dutch pediatric cancer patients[55]. This tool provides screening in the areas of structural resources, social support, child and sibling problems, general family problems, stress reactions and family beliefs. Hopefully, such screening instruments can shed more light on the progression of distress and adjustment in parents and children suffering from cancer. This could provide a basis for offering interventions to individual families. In line with the present study, it seems that not all families dealing with pediatric cancer have a need for specialized mental health care (the top of the pyramid). In the Dutch situation, many of the universal aspects of care for these families are part of the standard care procedures in hospitals providing treatment to pediatric cancer patients. By screening for difficulties, using questionnaires and interviews, we can tease out those who will need specialized care. In the Netherlands we propagate a system in which psychosocial problems and needs are assessed and discussed with every cancer patient regularly during curative or palliative treatment and follow-up (see guideline oncology

rehabilitation at: www.oncoline.nl). Assessment and discussion are the responsibility of the treating physician (medical specialist or GP) and the nursing team in the hospital or the home situation. In- and outpatient oncology teams work closely together with specialized psychologists, and social and pastoral workers providing psychosocial care to those referred. In this system basic supportive care is a standard in which needs are evaluated and care is tailored to the patients' needs in much the same way the PPPHM is set up. (Mission statement psychosocial care in the Netherlands, http://www.nvpo.nl/wp-content/uploads/2014/11/150717-Visie-PSOZ-opmaat-2.0_final.pdf).

Another promising new possibility can be found in internet based guided self-help programs such as recently reported on in the literature[57-59]. One such program has been shown to be effective for a small group of parents suffering from PTSS[58]. Internet self-help programs offer an opportunity to reach those who are unable to travel to or attend sessions in a clinic. Further research is needed in this area.

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